

Family Members End of Life Decision Making Experiences

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Abstract

Significance: The purpose of this study was to explore the experiences of individuals who accept the role of decision maker for a family member at the end of life, particularly focusing on their perspectives on their interactions with clinicians and the impact these interactions made on their decision-making process. With the completion of this study, the hopes are to develop a better understanding of the needs and of individuals making decisions for their family members at their end of life to ultimately improve the way clinicians interact with them.

Objective: To understand family members' experiences with end of life decision making including how clinicians interacted with them.

Method: Individual interviews were conducted with 10 family members who contributed to making an end-of-life decision for a family member. All individuals who were 18 or older, English speaking, and willing to discuss their experiences were eligible for the study. The participants were privately interviewed over the phone. For analysis of the data, a coding scheme was constructed by selecting significant components of the family members' experiences. The texts of the interviews were transcribed and coded allowing for the review of commonalities across the experiences.

Measurements: Qualitative interviews were used to describe experiences using a semi-structured interview guide. The interview guide was developed using the Ottawa Decision Support Framework, a guide for clients to use in decision-making regarding the health or social aspects of their life. This framework allows the interview and data to focus on evaluating the needs of the individual.

Main Results: Pending – data analysis is underway

Conclusions: Results will be used to understand needs and improve interactions with families making end of life decisions.

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